

2001 HIV/AIDS Consumer Survey

Make your voice heard!



***Influence funding
decisions that affect you!***

Are you living with HIV or AIDS?

If so, the Planning Council wants to know what services you use or need to help you get or keep health care. The Planning Council is a community group made up of people with HIV/AIDS and service providers. They decide how money from the Ryan White CARE Act gets spent in King County.

You can reach us at (206) 206-4527 or TTY (206) 205-5552

Please return this survey by January 31, 2001

**ALL RESPONSES ARE STRICTLY ANONYMOUS.
PLEASE DO NOT SIGN YOUR NAME ANYWHERE
ON THE SURVEY FORM.**

PART 1: WHAT SERVICES ARE YOU USING? WHAT CAN'T YOU GET?

STEP 1:

On the following pages, you'll find a list of services for people living with HIV/AIDS. For **each** of the services listed, put an "X" in **one** of the three boxes to tell us:

- if you currently need the service and are using it OR
- if it's a service you currently don't need OR
- if it's a service that you need, but can't get.

STEP 2:

For each service that you checked "Need, can't get," tell us the reason you feel you can't get this service. ***If you don't tell us what's wrong, we can't fix it!***

Some of the reasons people have mentioned include:

- Can't afford it
- Live too far away
- Don't feel welcome at the agency
- Don't know where to get it
- Not sick enough
- The service doesn't meet my needs

You can also mention other reasons.

EXAMPLE:

Service	Need and use	Don't need	Need, can't get	Why I can't get it... (It's IMPORTANT that you tell us!)
Dental care				
Support groups				

MEDICAL AND RELATED SERVICES

Service	Need and use	Don't need	Need, can't get	Why I can't get it... (It's IMPORTANT that you tell us!)
Medical care (doctor, nurse, etc.)				
Naturopathy, herbal medicine, etc.				
Acupuncture or Chinese medicine				

If you are currently using naturopathy, herbal medicine, acupuncture or other non-Western therapies, do you consider this to be your primary form of medical care? Yes ☐ No ☐

Dental care				
Treatment adherence support (help taking your HIV meds correctly)				
WA State prescription drug program ("APDP")				
Help paying for medical insurance				
Home nursing or infusion care				
Skilled nursing facility				
Hospice care				
Massage therapy				
Nutritional counseling				

IN-HOME SERVICES

Service	Need and use	Don't need	Need, can't get	Why I can't get it... (It's IMPORTANT that you tell us!)
Home chore <u>volunteer</u> (help with shopping, cooking, cleaning, etc.)				
Home care worker (<u>paid</u> attendant)				
Home delivered meals				

INFORMATION AND HELP GETTING SERVICES				
Service	Need and use	Don't need	Need, can't get	Why I can't get it... (It's IMPORTANT that you tell us!)
Medical information about HIV/AIDS, treatments, etc.				
Telephone referrals to medical or dental care				
Interpreter services				
Case management (having a professional help you get services and benefits)				
Peer or client advocacy (other than a case manager)				

COUNSELING, TREATMENT AND SUPPORT				
Service	Need and use	Don't need	Need, can't get	Why I can't get it... (It's IMPORTANT that you tell us!)
Professional mental health counseling or therapy				
Support groups				
One-to-one peer emotional support				
Spiritual or religious counseling				
Help <u>quitting</u> drug or alcohol use				
Help <u>managing</u> drug or alcohol use (harm reduction)				

HOUSING AND FINANCIAL HELP				
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Service	Need and use	Don't need	Need, can't get	Why I can't get it... (It's IMPORTANT that you tell us!)
Help finding low income housing				
Help paying rent				
Help paying utility bills				
Help paying for groceries				
Benefits counselor – SSI, SSD, etc. (other than case manager)				

SUPPORT SERVICES				
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Service	Need and use	Don't need	Need, can't get	Why I can't get it... (It's IMPORTANT that you tell us!)
Food bank/receiving free groceries				
Child care				
Transportation/rides				
Adult day health program				
Information/help with safer sex or safer drug use				
Legal assistance				

PART 2: WHAT SERVICES ARE MOST IMPORTANT TO YOU?

**Now we want to find out which services you consider to be MOST IMPORTANT for you.
You may check up to SEVEN (7) of the services listed below.
(Please don't check more than seven.)**

<input type="checkbox"/>	Acupuncture or Chinese medicine	<input type="checkbox"/>	Information/help with safer sex or safer drug use
<input type="checkbox"/>	Adult day health program	<input type="checkbox"/>	Interpreter services
<input type="checkbox"/>	Benefits counselor (other than case manager)	<input type="checkbox"/>	Legal assistance
<input type="checkbox"/>	Case management	<input type="checkbox"/>	Massage therapy
<input type="checkbox"/>	Child care	<input type="checkbox"/>	Medical care (doctor, nurse, etc.)
<input type="checkbox"/>	Dental care	<input type="checkbox"/>	Medical info about HIV, treatments, etc.
<input type="checkbox"/>	Food bank/receiving free groceries	<input type="checkbox"/>	Mental health counseling or therapy
<input type="checkbox"/>	Help finding low income housing	<input type="checkbox"/>	Naturopathy/herbal medicine/etc.
<input type="checkbox"/>	Help managing drug or alcohol use (harm reduction)	<input type="checkbox"/>	Nutritional counseling
<input type="checkbox"/>	Help quitting drug or alcohol use	<input type="checkbox"/>	One-to-one peer emotional support
<input type="checkbox"/>	Help paying for groceries	<input type="checkbox"/>	Peer or client advocacy (other than case manager)
<input type="checkbox"/>	Help paying for medical insurance	<input type="checkbox"/>	Prescription drug program of WA State ("APDP")
<input type="checkbox"/>	Help paying rent	<input type="checkbox"/>	Skilled nursing facility
<input type="checkbox"/>	Help paying utility bills	<input type="checkbox"/>	Spiritual or religious counseling
<input type="checkbox"/>	Home care worker (paid attendant)	<input type="checkbox"/>	Support groups
<input type="checkbox"/>	Home chore volunteer	<input type="checkbox"/>	Telephone referrals to medical/dental care
<input type="checkbox"/>	Home delivered meals	<input type="checkbox"/>	Transportation/rides
<input type="checkbox"/>	Home nursing or infusion care	<input type="checkbox"/>	Treatment adherence support (help taking HIV meds correctly)
<input type="checkbox"/>	Hospice care	<input type="checkbox"/>	Other: _____

PART 3:
TELL US ABOUT YOURSELF
(Remember, your answers are strictly ANONYMOUS)

What is your sex? (Check one)

- | | |
|---------------------------------|---|
| <input type="checkbox"/> Male | <input type="checkbox"/> Transgendered (M-to-F) |
| <input type="checkbox"/> Female | <input type="checkbox"/> Transgendered (F-to-M) |

What is your race/ethnicity? (Check all that apply)

- | | |
|--|---|
| <input type="checkbox"/> African American/Black | <input type="checkbox"/> Asian/Pacific Islander |
| <input type="checkbox"/> Alaska Native | <input type="checkbox"/> Caucasian/White |
| <input type="checkbox"/> American Indian/Native American | <input type="checkbox"/> Latino/Latina |
| <input type="checkbox"/> Other: _____ | |

What is your home zip code? _____

What is your age? _____

What is your annual household income (before taxes)? (Check one)

- | | |
|--|--|
| <input type="checkbox"/> Under \$8,500 | <input type="checkbox"/> \$25,001 - \$30,000 |
| <input type="checkbox"/> \$8,501 - \$17,000 | <input type="checkbox"/> \$30,001 - \$40,000 |
| <input type="checkbox"/> \$17,001 - \$25,000 | <input type="checkbox"/> Over \$40,000 |

Do you have any dependent children living with you?

- ☐ No
- ☐ Yes If "yes," how many dependent children are living with you? _____
- What are their ages? _____

How do you believe you became infected with HIV? (Check all that apply)

- | | |
|--|---|
| <input type="checkbox"/> Sex with a man | <input type="checkbox"/> Blood transfusion |
| <input type="checkbox"/> Sex with a woman | <input type="checkbox"/> Blood products/clotting factor |
| <input type="checkbox"/> Sex with an injection drug user | <input type="checkbox"/> Don't know |
| <input type="checkbox"/> Sharing drug needles or works | <input type="checkbox"/> Other: _____ |

How do you identify yourself? (Check one)

- | | |
|--|---------------------------------------|
| <input type="checkbox"/> Straight/heterosexual | <input type="checkbox"/> Bisexual |
| <input type="checkbox"/> Gay/lesbian | <input type="checkbox"/> Other: _____ |

What is your HIV status? (Check one)

- ☐ HIV positive, without symptoms
- ☐ HIV positive, with symptoms
- ☐ AIDS diagnosed (based on low T-cell count)
- ☐ AIDS diagnosed (based on opportunistic infections)

What is your current T-cell count? (Check one)

- | | |
|-------------------------------------|--|
| <input type="checkbox"/> Don't know | <input type="checkbox"/> Between 200 - 500 |
| <input type="checkbox"/> Under 200 | <input type="checkbox"/> Over 500 |

What is your current viral load? (Check one)

- | | |
|--|---|
| <input type="checkbox"/> Don't know | <input type="checkbox"/> Between 1,001 - 10,000 |
| <input type="checkbox"/> Undetectable or below 200 | <input type="checkbox"/> Between 10,001 - 100,000 |
| <input type="checkbox"/> Between 200 - 1,000 | <input type="checkbox"/> Over 100,000 |

In the past twelve months, have you (Check all that apply):

- ☐ Been in jail or prison
- ☐ Been homeless (no permanent address)
- ☐ Used needles to inject street drugs
- ☐ Used other street drugs

Have you ever been diagnosed with a mental illness?

- ☐ Yes
- ☐ No

What kind of place do you currently live in? (Check one)

- | | |
|--|--|
| <input type="checkbox"/> Your own house or apartment | <input type="checkbox"/> Jail or prison |
| <input type="checkbox"/> In a friend or relative's house/apartment | <input type="checkbox"/> Drug/alcohol treatment center |
| <input type="checkbox"/> Hospice or nursing facility | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Live on the streets or in a shelter | |

Do you currently live in housing that you qualified for by having AIDS?

- ☐ Yes
- ☐ No

Are you currently taking any of the following medications for your HIV infection? (Check all that apply)

- ☐ Antiviral medications (AZT, ddI, d4T, nevirapine, Combivir, Epivir, abacavir, Sustiva, etc.)
- ☐ Protease inhibitors (invidinavir (Crixivan), saquinavir, ritonavir, nelfinavir, Amprenavir, etc.)
- ☐ Drugs to treat or prevent opportunistic infections

Are you having problems taking your HIV meds as prescribed?

- ☐ No
- ☐ Yes

If "yes", what are the reasons? (Check all that apply)

- | | |
|---|---|
| <input type="checkbox"/> Too many pills | <input type="checkbox"/> Don't have stable housing |
| <input type="checkbox"/> I forget when to take them | <input type="checkbox"/> Don't like to be reminded I have HIV |
| <input type="checkbox"/> Bad side effects of the meds | <input type="checkbox"/> Too busy |
| <input type="checkbox"/> Afraid people will find out I have HIV | <input type="checkbox"/> Other: _____ |

What or who helps you to take your meds as prescribed? (Check all that apply)

- | | |
|--|---|
| <input type="checkbox"/> No one; I don't need any help | <input type="checkbox"/> Another HIV+ person |
| <input type="checkbox"/> Doctor/nurse | <input type="checkbox"/> Mediset (pill box) or timers |
| <input type="checkbox"/> Case manager | <input type="checkbox"/> Pharmacist |
| <input type="checkbox"/> Family/partner/roommate | <input type="checkbox"/> Other: _____ |

PART 4:

WHAT SERVICES HELP YOU GET OR KEEP MEDICAL CARE?

A lot more attention is being paid these days to helping people with HIV or AIDS get and keep the medical care they need.

Please tell us which services you think are the most important in helping YOU get medical care or keep the medical care you're using.

**You may check up to SEVEN (7) of the services listed below.
(Please don't check more than seven.)**

<input type="checkbox"/>	Acupuncture or Chinese medicine	<input type="checkbox"/>	Hospice care
<input type="checkbox"/>	Adult day health program	<input type="checkbox"/>	Information/help with safer sex or safer drug use
<input type="checkbox"/>	Benefits counselor (other than case manager)	<input type="checkbox"/>	Interpreter services
<input type="checkbox"/>	Case management	<input type="checkbox"/>	Legal assistance
<input type="checkbox"/>	Child care	<input type="checkbox"/>	Massage therapy
<input type="checkbox"/>	Dental care	<input type="checkbox"/>	Medical info about HIV, treatments, etc.
<input type="checkbox"/>	Food bank/receiving free groceries	<input type="checkbox"/>	Mental health counseling or therapy
<input type="checkbox"/>	Help finding low income housing	<input type="checkbox"/>	Naturopathy/herbal medicine/etc.
<input type="checkbox"/>	Help managing drug or alcohol use (harm reduction)	<input type="checkbox"/>	Nutritional counseling
<input type="checkbox"/>	Help quitting drug or alcohol use	<input type="checkbox"/>	One-to-one peer emotional support
<input type="checkbox"/>	Help paying for groceries	<input type="checkbox"/>	Peer or client advocacy (other than case manager)
<input type="checkbox"/>	Help paying for medical insurance	<input type="checkbox"/>	Prescription drug program of WA State ("APDP")
<input type="checkbox"/>	Help paying rent	<input type="checkbox"/>	Skilled nursing facility
<input type="checkbox"/>	Help paying utility bills	<input type="checkbox"/>	Spiritual or religious counseling
<input type="checkbox"/>	Home care worker (paid attendant)	<input type="checkbox"/>	Support groups
<input type="checkbox"/>	Home chore volunteer	<input type="checkbox"/>	Telephone referrals to medical/dental care
<input type="checkbox"/>	Home delivered meals	<input type="checkbox"/>	Transportation/rides
<input type="checkbox"/>	Home nursing or infusion care	<input type="checkbox"/>	Treatment adherence support (help taking HIV meds correctly)

PART 5:
ARE THERE ANY OTHER COMMENTS
THAT YOU WOULD LIKE TO SHARE WITH US?

**Thanks again for filling out this survey. We greatly appreciate it.
Your responses will help the Planning Council
make important funding decisions.**

**Please tell your friends about this survey – we'd like to hear from as many
people living with HIV/AIDS as possible.**

**Fold your survey and tape it closed,
and drop it in the mail by January 31, 2001.**